



MFTD Waiver Families

www.SaveMFTDWaiver.com
mftdwaiver@gmail.com

Children on Medical Technology and the 1115 Waiver

Nearly three decades ago, Medicaid waivers began in large part because of Katie Beckett, a young child dependent on a ventilator, whose plea to live at home was ultimately granted by President Ronald Reagan. As Illinois contemplates restructuring its Medicaid program, the state must remember the original mission of children's Medicaid waivers: to provide care at home to children who use medical technology, including ventilators, tracheostomies and central intravenous lines. In Illinois, the Medically Fragile Technology Dependent (MFTD) waiver serves this purpose, providing access to private duty nursing and "wrap-around" Medicaid coverage to supplement inadequate private insurance plans, which are not required by the state to cover nursing.

Children in the MFTD waiver currently make up less than 0.02% of Illinois Medicaid recipients. Because this population differs considerably from most Medicaid participants and is small in number, their unique needs would be easy to overlook. They are, however, arguably Illinois' most vulnerable and needy population, due to their life-threatening medical conditions. It is critical that Illinois continues to appropriately serve these children through a robust Medicaid program including private duty nursing services.

The MFTD waiver is one of Illinois' success stories, and has served as a model for other programs in the country. It has been financially stable for years and has dramatically improved health outcomes, with children only requiring the program for an average of five years. In the past few years, however, cost-cutting measures have lessened the efficacy of this program. Areas that require improvement in order to comply with federal disability laws and avoid *Olmstead*-related litigation include:

1. **Nurse staffing:** Only 60% of physician-prescribed hours are provided, in large part because pay rates have not been increased in a decade, and were actually cut in 2012.

2. **Nurse training and quality:** A large percentage of nurses are inadequately prepared to work in a home environment, and many have never been trained on medical technology. Training that does occur is unpaid and unreimbursed in most cases.
3. **Care coordination:** Care coordination is fragmented, with many services duplicated, while other services are not addressed at all.
4. **High hospitalization rates and long hospitalizations:** Because nursing is not always available and emergency in-home services are not covered, many children end up being unnecessarily hospitalized.
5. **Frequent reductions in private duty nursing hours:** Almost all children have had their hours reduced in the past few years, even without a change in medical status, and in direct contradiction to physician plans of treatment. From 2009-11, appeal hearings increased more than 1000%.

Innovations: Service Improvements and Efficiencies for the 1115 Waiver

Over the past two years, families of children in the MFTD waiver have fought to save this vital program. In order to improve the program, we have developed many innovative strategies to reduce costs while simultaneously improving patient care.¹ These include:

1. **Comprehensive care coordination program.** Currently, children in the MFTD waiver receive fragmented yet often duplicated care coordination services from the Division of Specialized Care for Children (DSCC) and their assigned nursing agencies. While this care coordination is helpful, many families feel frustrated that DSCC is powerless to actually coordinate care, and services are frequently duplicated by different agencies. For example, medication reconciliation is performed repeatedly, by the child's physician, the home nurse, the nursing agency supervisor, the DSCC case manager, and finally by HFS pharmacists, often every 1-2 months. We propose a comprehensive care coordination program that includes an overseeing complex care physician, care coordination nurse and social worker or case manager. Care coordination nurses would combine nursing supervisory and case management tasks in order to eliminate duplication.
2. **Staffing incentive program.** Currently, families struggle with abysmal nurse staffing, and parent caregivers routinely need to be awake for periods of up to 4 days because of poor staffing. We propose

¹ See <http://savemftdwaiver.com/reports/costcutting.pdf> for the complete proposal.

a system in which at least 80% of EPSDT-required private duty nursing services must be provided.

Whenever staffing exceeds 90%, nursing agencies could receive incentive payments. Any time a child is staffed below 80%, the family can choose to bank unused hours for future use, or cash in unused hours to pay for homemaker services or missed work pay that occurred due to poor staffing.

3. **Reserved capacity program.** Many families are concerned about the addition of a wait list for services in a universal HCBS program. In order to guarantee that children can immediately access home care, we suggest reserving a minimum of 1000 spots for children with medical technology. Unlike most 1915(c) waivers in Illinois, the MFTD waiver does not have—and has never had—a waiting list. It is extremely costly to care for these children in hospitals, and transitioning children out of the hospital and into the home saves the state more than \$30,000 per child per month.²
4. **In-home and telemedicine services.**³ Primary and complex care in-home visits by physicians, as well as in-home labs and imaging, should be added as covered services. A similar program for Boston's MFTD population is saving about \$1 million per year.
5. **Emergency response program.** To help keep children out of the ER and hospital, advanced practice nurses should be available for consultation 24 hours per day, both for families and home nurses in emergency situations. Services could be provided via phone, telemedicine, or home visits.
6. **Maximizing third party liability.**⁴ In the past, we have proposed that insuring as many MFTD children as possible through private insurance, and requiring insurers to cover private duty nursing, could save Illinois as much as \$12 million yearly.
7. **Use of electronic medical records between nursing agencies, care coordination teams and medical facilities.** This strategy would eliminate paperwork, resolve medication and skilled nursing inconsistencies, and streamline care.
8. **Implementation of a nurse training, monitoring and evaluation program to reduce staff turnover and provide better continuity of care.** Nurses are not currently receiving adequate training to work in home care settings. This program would allow nurses to receive payment incentives for completing

² See <http://savemftdwaiver.com/costneutrality.html> for analysis and examples.

³ Our cost-cutting proposal, available at <http://savemftdwaiver.com/reports/costcutting.pdf>, contains information on home visiting services. See also <http://homvee.acf.hhs.gov/> for evidence-based information.

⁴ See <http://savemftdwaiver.com/reports/costcutting.pdf> for detailed analysis on third party liability and MFTD populations.

a home care and medical technology training course. In-home nurse training for each case would be a covered service, and nurses would receive back pay for in-home training after working on the case for a period of one month. Nurses would also be paired with mentors in a continuous monitoring and evaluation relationship. Illinois may also want to consider creating a state-run nursing agency to reduce costs and streamline care.

9. **Development of a DME loan and maintenance program.** Children often receive durable medical equipment that is quickly outgrown or no longer needed. Instead of purchasing new items for each child, these items can be loaned to families, resulting in significantly lower costs. In order to ensure the integrity of items, all durable medical equipment, whether purchased or loaned, would be maintained at least yearly at no charge to the family.
10. **Concurrent palliative care option.**⁵ Currently, Medicaid will not reimburse visiting palliative nurse services or other palliative care options for children receiving private duty nursing. Given the changing understanding of pediatric palliative care in the ACA as a comprehensive lifelong approach to children with life-limiting conditions, these services should not only be covered, but should also be encouraged, as they will dramatically reduce hospitalizations and medical complications.

Guiding Principles for Children Who are Medically Fragile and Technology Dependent

After the MFTD waiver was nearly eliminated/modified in 2012, families are understandably hesitant that any new program will meet their children's needs. The following eight principles represent the integral parts of this program that must continue in order to prevent another *Olmstead*-related lawsuit:

1. **Children must continue to receive full Medicaid coverage, including comprehensive EPSDT benefits such as private duty nursing care, without limits, caps or restrictions.**
2. **Eligibility should be offered to children of all income levels, using institutional income and resource rules without regard to parental income.** Most families would otherwise have \$200,000 annually in uncovered expenses, and our research has demonstrated that even families making more than 1000% FPL are unable to care for their children without the MFTD waiver.⁶

⁵ On palliative care in this population, see <http://savemftdwaiver.com/reports/costcutting.pdf>.

⁶ See <http://savemftdwaiver.com/incomecaps.html>, point #3 and graph, for detailed analysis.

3. **Any universal screening tool needs to be able to capture and weight the unique technology and skilled nursing needs of this population.** We request that pediatric complex care providers vet any universal screening tool for suitability to ensure children with medical technology are not denied critical services based on an incomprehensive tool.
4. **Cost sharing is not allowable under Medicaid rules for children and should not be imposed.** The experience of other states such as Idaho and Wisconsin has shown that cost sharing for children on medical technology does not increase revenue, and instead leads to poorer health outcomes.⁷ It can also cause families to drop private insurance, raising costs to the state. Cost sharing for this population will lead to increased institutionalization, increased morbidity, poorer health outcomes, and increased longitudinal medical expenses.
5. **Private duty nursing services, as long as the cost is less than care at a pediatric hospital, must be available to these children.** Illinois has certified that most children in the MFTD waiver are unable to live in a nursing facility, and must be cared for in a hospital if they cannot live at home with supportive services.⁸ Restricting children to standard budgets or numbers of hours of care based solely on the cost of care at a nursing facility will inevitably fail to meet these children's needs, leading to increased institutionalization, morbidity and mortality.
6. **Services must be available immediately without a waiting list.**
7. **Children in this program cannot be placed in Medicaid managed care programs since a large percentage of children also hold private insurance, including children covered by private HMOs, who only use Medicaid as secondary or "wrap-around" insurance.**
8. **Nurses must not be replaced with unlicensed care providers, such as CNAs or PAs.** Children with medical technology cannot be cared for safely without the use of appropriately licensed nurses. Lives are put in jeopardy when a family is offered the option to use an untrained or unlicensed provider in order to extend the number of hours of services they can receive. In addition, using unlicensed providers violates Illinois' Nurse Practice Act for children with tracheostomies and central lines.

⁷ To read our comprehensive research paper on cost sharing for MFTD populations, please see <http://savemftdwaiver.com/reports/costsharing.pdf>.

⁸ For more information on this important issue including detailed analysis, please see <http://savemftdwaiver.com/reports/LOC.pdf>.